The Mentally Retarded Infant

Is Placement Feasible?

ELLEN S. ALKON, M.D., M.P.H., AND RONALD L. THIELE, M.D., M.P.H., *Berkeley*

■ *A 1968 questionnaire about placement resources for mentally retarded infants that was sent to public agencies in all 58 California counties showed:*

- *Resources for counseling, placement, and financial aid for out-of-home placement are not uniformly available to all groups within the population.*
- *Financial help with out-of-home placement of a member of a family that is not medically indigent may be available in less than one-fourth of the counties of the state.*
- *Knowledge of resources is often inadequate. A family could be referred inappropriately from one agency to another.*

RETARDED INFANTS need both immediate and long-term continuing care. When such an infant is first identified, the family and the physician usually discuss plans to obtain this care. Although the majority of retarded infants can be cared for by their own family, some families are advised or may desire to seek immediate out-of-home placement. Other infants have special nursing and medical care needs, such as tube feeding or respiratory support, which may necessitate prolonged hospital care. Several steps should be taken before placement is recommended and before families make such a decision:

- Accurate diagnosis and determination of the infant's medical or nursing needs.
- Counseling with parents to help them cope with their feelings, appraise their capabilities of care, and determine if placement is desired.
- Location of appropriate resources to assist the family including short or long term financially feasible out-of-home placement, if this is desired.

The present study was undertaken to determine the availability of specific resources within public agencies in each California county to fulfill the needs of families for counseling and locating resources, including financially feasible out-of-home placement for mentally retarded infants.

In January 1968 a specially designed short questionnaire was sent to all California county welfare departments,[1] city and county health departments,[2] county probation departments,[3] county general hospitals,[4] and the state hospitals for the mentally retarded and their four outpatient units. Twenty-four persons, professional and lay, serving in an official coordinating and planning capacity for Mental Retardation in their county or region also were queried.

From the Division of Maternal and Child Health, University of California, School of Public Health, Berkeley.

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TABLE 1.—*Services for Mentally Retarded Infants Reported by California Public Agencies in 1967*

	Local Facilities				State Hospital Out-patient Units
	County General Hospital	*Health Department*	*Welfare Department*	*Probation Department*	
Agencies identified, and percent responding	51 (82%)	61 (100%)	58 (95%)	58 (93%)	4 (100%)
Agencies having serviced a family with a retarded infant	21	33	25	27	4
Agencies offering some kind of parent counseling	23	59	52	no answer	4
Agencies offering help locating community placement	21	20	45	35*	no answer

*35 respondents thought the court would be likely to order out-of-home placement for the infant if the court could gain jurisdiction.

TABLE 2.—*Admission Policies for Retarded Infants at 42 California County General Hospitals in 1967*

Infant's care needs	*Admission Policies*	
	Short term care only	*Prolonged care*
Needs special care	22	17
No special care needs	27*	6

*Five of these hospital accept infants with no special care needs only on court referral.

Results

Analysis of the questionnaire responses indicated that patterns of counseling services, location and arrangement for out-of-home placement and financial assistance for placement are unique to each county. Some of the responses are summarized in Table 1.

County General Hospitals

Twenty-one county general hospitals reported that they cared for a retarded infant in 1967, but these hospitals were not always among the 23 hospitals which could offer parent counseling, or the 21 hospitals which could help locate community placement. The usual service of the county hospital was interim placement with a usual duration of hospital care of less than one month, although prolonged care may be offered (see Table 2).

Each of the 39 hospitals who would admit a retarded infant, including the five hospitals which are restricted to the medically indigent, charge fees. Eighteen of the 39 hospitals charge everyone full fees, and ten of these 18 may require a property lien.

Health Departments

While 33 of the 61 local California health departments reported service for the family of a retarded infant in 1967, 59 offered parent counseling, and 20 could help locate community placement.

Welfare Departments

Although 52 of the 55 responding county welfare departments could counsel families with a retarded infant and 45 could help locate community placement, the families' financial status may determine who can receive service. Six of the departments could only provide these services for families on public assistance, and an additional three could provide service only if the family was on public assistance or medically indigent (eligible for Group II Medi-Cal). Seven welfare departments that offer counseling reported a serious limitation in this service, and many departments indicated a scarcity of adequate resources for community placement.

While 48 welfare departments reported that they could offer financial assistance for out-of-home placement of a retarded infant if his family was on public assistance, only six could offer financial assistance with placement to the family who did not qualify as medically indigent or eligible for public assistance.

Probation Departments

Homeless and mistreated children and retarded children whose families are found by the court to be unwilling or incapable of "exercising proper and effective parental care"[5] can be made wards of the court, and hence a public responsibility.

Thirty-three county probation departments in California process applications to the state hospitals for the mentally retarded; in spite of this, only eight of these 33 replied that the placement of a retarded infant is a proper concern of the probation department. Thirty-five of the respondents thought their county court would likely order out-of-home placement if the parents were found to fit the above description, and an additional seven *might* order out-of-home placement. Although 13 counties reported that out-of-home placement was unlikely, some of these reported actually handling similar cases through out-of-home placement. Forty probation departments reported foster home placement. County hospitals and shelter care in detention facilities are also utilized.

State Hospitals for the Mentally Retarded

Four state hospitals in California provide nursery care for retarded infants. In 1967 admission to these hospitals was possible in less than three weeks for infants with special problems needing medical care in a hospital. Healthy retarded infants without special care needs, on the other hand, are not eligible for rapid admission. Thus no state hospital admitted healthy infants with Downs' syndrome during 1967, and patients with this condition were actually admitted at average ages from four to nine years.

Outpatient Units

Each of the four state hospitals for the retarded has an outpatient unit available to residents within its region. All offer family counseling although one of them is able to offer only short-term counseling. Two also offer physician consultation. All may offer pre-admission study, and may expedite the admission of the newborn with special care needs. The mother's inability to care for her infants, or the lack of community resources alone would not be sufficient reason for admission, according to two of the outpatient units.

Mental Retardation Coordinators

Of the 24 questionnaires sent to individuals in mental retardation planning and coordinating positions, 21 (88 percent) were returned. The respondents reported only those resources also mentioned by the public agencies. Many commented on the problem of inappropriate referrals and the lack of coordination of existing resources for the retarded.

Referrals

When a family does not meet the eligibility requirements of an agency or needs help other than what is offered, they should be appropriately referred. Of the respondents, 76 percent of the county hospitals, 87 percent of the health departments, 78 percent of the welfare departments and 51 percent of the probation departments reported where they referred these families.

Most of the reported referrals were from one public agency to another public agency. Welfare departments received referrals from 45 percent of the county hospitals, 41 percent of the health departments, and 36 percent of the probation departments which recorded referrals. The welfare departments, in turn, would make their referrals to health departments, probation departments, and one of the divisions of the Department of Mental Hygiene. Only 14 percent of all responding agencies would refer a family to a community mental health (Short-Doyle) program.

Although many referrals were appropriate for the service desired, many inappropriate ones were reported. For example, nine agencies mistakenly refer to Crippled Children's Services for help with out-of-home placement. Five agencies would refer to the probation department in counties where the court is unlikely to order out-of-home placement. Four agencies reported referring cases to the welfare department in counties where placement help is not offered by the welfare department. Six agencies mentioned a regional center for mental retardation in counties where no such center existed, and one mentioned referral for placement to a health department which does not offer placement assistance.

Some form of information and referral service for the mentally retarded was reported to exist in 30 (52 percent) of the California counties. However, utilization is obviously incomplete, for in five of these counties agencies disagreed about the existence of such a service.

Discussion

We recognize the following limitations in interpretation of the responses to the questionnaire: (1) Each questionnaire was filled out by one individual within an agency; this person may have interpreted the questions or his own agency policy differently from what might have been the interpretation by another individual in the same agency; (2) The questionnaire possibly may not have

elicited information on all community resources; (3) The answers given may reflect only the policy of the agency as stated by the individual respondent at that moment; (4) The questionnaire asked only for specific information on the existence, not the quality or adequacy of service. Nevertheless, we think that certain trends are apparent and that these are of importance to professionals who serve families with retarded children.

Initial identification of the retarded infant is generally made by the attending physician.[6] Further evaluation may be available in one of the highly skilled diagnostic units which are accessible to some areas of the state. These evaluation services can provide an important resource for family counseling.

A recommendation for placement is likely to produce the desire for placement,[7] regardless of the feasibility or suitability of such a step. All families, regardless of their social and financial status, need immediate counseling to help them with their feelings about their new retarded infant, to plan realistically and to implement these plans. The physician having the first contact with the family should initiate the counseling process.[8] Helping a family emotionally before they reach a decision, and guiding them to realistic resources is a job which usually is best done by a counselor in collaboration with a physician. Our study indicated that resources for professional collaboration in this process, even if not uniform in every community, are sometimes available.

The decision to seek out-of-home placement of the infant may be reached by some families. At this point, further direction and assistance are needed in locating the resources to provide that care. If according to the state hospital an infant requires hospital care, admission to a state hospital is reportedly possible within a short time. If the infant is not eligible for a state hospital, then community placement is the only alternative.

County hospitals serve as a temporary resource in many areas. Although directories of approved placements are available, individual families are rarely equipped to judge the suitability of these homes for their infant. The availability of professional help with placement may be financially determined. Infant placement in some counties is not possible because of insufficient resources.

Financial Help

Even if placement seems appropriate for the infant and the family, it may be financially impossible or economically destructive. The quoted cost for a placement usually does not include clothing, medical care, and incidental expenses. In 1965 the average annual cost of maintaining a retarded child in out-of-home community placement in Los Angeles was estimated to be in excess of $2,000.[9] This cost was based on a fee of $105 to $175 per month. The current cost is undoubtedly higher since the monthly fees in a nursery facility in 1967 is Los Angeles ranged from $135 to in excess of $285.[10]

Financial assistance with placement was reportedly available from welfare departments in 48 of 53 counties for families eligible for welfare, in 13 of 48 counties for families considered medically indigent, and only in six of 49 counties for families not medically indigent. For families to whom this assistance is not available, several other resources may be considered:

- Private foundations sometimes offer temporary help.
- Probation departments do assume responsibility for some infants if the family undergoes the ordeal of having itself found unwilling to exercise care of the infant.
- Regional centers, in the counties they serve, within the limits of staff time, participate financially in a program that meets the particular needs of the individual.
- The Bureau of Social Work, California Department of Social Welfare, can place a limited number of retarded children in the community as an alternative to state hospital placement.
- Armed forces personnel dependents have financial aid available to them for out-of-home placement from the military dependents medical care program.

Despite these resources, out-of-home placement will be impossible for many families because financial assistance is not available to them. Only 14 (24 percent) of the counties reported some mechanism other than probation to help pay for out-of-home placement when the family is not medically indigent.

Unless emotional, situational and financial help are available, it may be impossible to implement a recommendation for out-of-home placement of a healthy retarded newborn. If a family receives this recommendation but can not place the infant, their iatrogenic desire to have the infant out of their home may produce unnecessary misery.

Therefore, a physician helping a family plan for the care of a retarded infant should be aware both of the need for counseling to help the family reach a suitable plan and the real limits which are posed by the scarcity and expense of suitable community placement.

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PSYCHIATRIC REFERRAL FOR TEEN-AGER DRUG USERS

What are your indications for referring a teen-ager who is a drug user to a psychiatrist?

"I think that one of the main danger signs in dealing with adolescents is depression; which is, after all, sometimes the precursor to suicide. . . . In talking with young people, I think one should gauge the depth of the depression carefully and face up to the issue of suicide. . . . These young people aren't afraid to talk about suicide. Some of them enjoy talking about it, and these are probably the ones that you need to worry less about. The ones who express real worry about what they may do to themselves and who are contemplating some particular method of committing suicide certainly should be referred immediately for some kind of psychiatric help.

"[Two other considerations are important in thinking about referral.] One is if you feel that you're not communicating with your patient—that you don't understand what he is saying, or you're on another wave length, or somehow you're not meeting—this is a reason to refer. It may just be that he doesn't like you very much; but it may also mean that he feels unhappy because he hasn't made contact, and this may make him more frustrated and more desperate. The other thing, which is a clue, is your own anxiety level. If you're talking with a patient, and for some reason he makes you very nervous and upset and scared and you start dreaming about him at night, this is a good reason to get somebody else to see him and size up the situation."

—GRAHAM B. BLAINE, JR., M.D., Boston

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